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Economic and Social Commission for Western Asia (ESCWA)

Report

**Workshop on establishing an Arab Disability Indicator Framework
and improving data collection on persons with disabilities
InterContinental Semiramis Hotel
Cairo, 19 September 2018**

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Background

1. On 18-20 September 2018, ESCWA held the first meeting bringing together statisticians and policymakers from Arab countries to discuss refining the collection of data on persons with disabilities. The aim of the Inter-agency and Expert Group Meeting on Improving Disability Statistics in the Sustainable Development Goals was to start developing a Framework of Disability Indicators for the Arab region to be used for collecting and analyzing disability statistics. Participants also reviewed best practices for collecting data in accordance with methodologies developed by the Washington Group on Disability Statistics.
2. The meeting was attended by thirteen countries in the Arab region (Egypt, Iraq, Jordan, Kuwait, Libya, Mauritania, Morocco, Oman, Palestine, Qatar, Sudan, Tunisia and Yemen) and by international experts and representatives of UN agencies, civil society and Disabled People's Organizations (DPOs).
3. On 19 September, the policymakers broke into a separate group from the statisticians to identify their needs and gaps when using statistics for policy-making. Policymakers also explored other data sources which they use to supplement survey and census data collected by National Statistics Offices (NSOs). This meeting report summarizes those discussions.

I. RECOMMENDATIONS

- The main priorities for establishing indicators on accessibility include accessibility of transportation, infrastructure/public buildings/pavements, and services;
- To measure accessibility, a checklist is needed to establish a standardized method of assessing and rating each building;
- Persons with disabilities should be involved in design and monitoring efforts;
- The main priorities for establishing statistical indicators on health include the availability, accessibility and affordability of health services as well as affordable medical services;
- Another possible indicator could be the percentage of the population of persons with disabilities receiving free health services;
- Statistics do not provide information about the quality of services, which is critical for policymakers to know how to improve policies and services;
- DPOs should participate in training enumerators for censuses and surveys to have a correct understanding and a better identification of persons with disabilities.

II. SUMMARY OF DISCUSSIONS

4. Ms. Gisela Nauk (Chief, Inclusive Social Development Section, Social Development Division, ESCWA) introduced the main purpose of the workshop, which was to identify policymakers' priorities for measuring disability for policymaking to be improved. Demographic data was improving, such as age, location, and gender of persons with disabilities, but when it came to inclusion in society, the available indicators were still limited. She asked participants to share the kind of data they were currently using in developing policies, and where the data came from. Oman, for example, had a complete population register that was used for sourcing data. Lebanon had a registry for disability cardholders which was used for policymaking, but it was not known how complete this registry was since it relied on self-identification. It was nonetheless a useful source of information.

5. Mr. Hussein Abu-Farrash (Director of Policies and Development, Higher Council for the Rights of Persons with Disabilities, Jordan) said that they used data from the census and statistics acquired by the NSO, but that the Higher Council was working on certain priorities, such as inclusive education or employment, without proper indicators. For example, when working on the issue of housing for children with disabilities, they used data

collected during a field study by another organization which assessed the situation of individual children in specialized homes. The Higher Council would not have been able to carry out this kind of survey on their own. They used administrative records on an as-need basis, for example to see how many people were enrolled and lived in shelters or homes. Administrative records were not used for statistical purposes but to provide guiding information when forming policies. For example, to find out how many persons with disabilities were employed in the private sector, information was provided by the Ministry of Labour. However, administrative records needed to be dealt with carefully because they did not necessarily reflect accurate figures and because people with mild disabilities might not be identified or recorded in administrative registers.

6. Mr. Amin Inabi (General Manager, Directorate of Persons with Disabilities, Ministry of Social Development, Palestine) commented on the situation in Palestine which was not so different from Jordan where they relied on different sources for acquiring data. Various ministries provided the Ministry of Social Development with data depending on the issue, e.g. Labour, health, etc. Palestine also had very strong and professional civil society organizations (CSOs) specializing in different issues and which provided relevant data in addition to being a good source of contacts. They had also helped lead the national strategy on disability under development since 2013. The Washington Group approach provided a good source of data as well as important guidelines for collecting data.

7. Dr. Mervat Al-Samman (President of the Egyptian Federation of Associations of Persons with Disabilities, Egypt) noted that the Egyptian constitution included 14 articles that addressed the rights of persons with disabilities, in addition to Law no. 10 of 2018 which was cross-cutting and comprehensive, but which would require proper implementation. On the issue of data, Egypt did not have accurate statistics on persons with disabilities because several agencies were responsible for data production. For example, the Ministry of Social Solidarity used data from the Karama registry, the Ministry of Health had a medical committee which identified persons with disabilities, the Ministry of Labour had a registry of persons with disabilities employed in various sectors, but it only included individuals 18 years of age or older. The Ministry of Education, which had issued a decree on inclusive schools, had a list of schools that provided specialized services to persons with disabilities. In Aswan, CSOs carried out a survey of people with disabilities in 2012 and identified 47,000 individuals, though most likely it did not capture everyone. If CSOs collaborated with the government, they could carry out this kind of survey on a larger scale and it would be more accurate and less costly. CAPMAS had the official figures on persons with disabilities, but those figures were different from the data collected by Ministries.

8. Ms. Nauk highlighted that, as in Egypt, the identification of persons with disabilities often varied by ministry, so they were not comparable either across ministries or with the data collected by NSOs. Good policies were being produced based on persons who had been identified, but there were many people with disabilities who had not been identified. She posed the question of how to use survey data which was standardized so that definitions would be uniform.

9. Ms. Aziza Noman (Public Relations Director, National Fund for Persons with Disabilities, Yemen) said that her organization did not rely on national statistics but instead conducted surveys through independent organizations. The census conducted in Yemen had a major gap because some families concealed that there was a person with disability in their household and the disability rate was therefore only two per cent. Afterwards, field visits were conducted and when people were informed that they would receive financial support or other benefits, more families came forward and provided accurate information which was used to formulate policies.

10. Mr. Bdraldeem Mohamed (Secretary General, National Council for People with Disabilities, Sudan) said that in Sudan they found it very difficult to acquire true and accurate data for reporting on persons with disabilities. Statistics were usually non-existent or deficient, including data from specialized surveys or civil registries. When organizations working with persons with disabilities did their own surveys, their results were very different. There was a need for a single standardized definition for all surveys using a simplified survey form, and survey workers should be properly trained to guarantee a minimum standard of accuracy in line with

international standards and best practices. Data should be linked with the SDGs and should be disaggregated by disability across all categories.

11. Ms. Jahda Abou Khalil (General Director, Arab Organization of Persons with Disabilities (AOPD), Lebanon) stated that in Lebanon policies were formulated based on the data from the 98,000 persons who possessed a disability card issued by the Ministry of Social Affairs. This registry included detailed information about everyone, the type of disability and the education level. The card required the Ministry of Health to provide full medical treatment to cardholders. Unfortunately, most benefits went to persons with physical disabilities. Lebanon had seven different sign languages for the Deaf and hard of hearing, so they had difficulty communicating. Hence the need to unify the sign language.

12. Ms. Alkhansa Alhusaini (Director of Planning and Research Division, Public Authority for Disability Affairs (PADA), Kuwait) commented that in Kuwait they did not use data from statistical surveys because they did not provide a full and complete picture. Instead, they used the data of the 150,000 people registered with PADA. This number increased significantly after the State expanded financial benefits. The data they received from other Ministries were different from their own numbers.

13. Dr. Ayman Eldeep (Director, Directorate of Family and Psychological Counselling, Shafallah Center for Persons with Disabilities, Qatar) noted that the relationship between statisticians and policymakers was an important topic, and this workshop bringing them together was a positive step. There was a long way to go to identify accurate data about persons with disabilities. He posed several questions: Did policymakers know how to read and interpret figures collected by statisticians? How could the numbers of persons with disabilities collected by censuses be linked to the rights-based approach? What would happen after receiving these numbers? Were the numbers to be used only for reference or to formulate policies? Did the organization that collected the data delve deeply into the types of disabilities? Were these figures known to only a few specialized people or were they known to families and the media? How could they be shared with concerned parties? Numbers should be translated into services, which required additional effort. There should be one single entity or unit in each country to deal with and disseminate this data. It was important to unify concepts and terminologies that had a scientific basis, like the definition of disability in the USA. For example, some countries classified autism as an illness and others as a disorder.

14. Ms. Raja Bin Brahim (Director of Solidarity and Social Development, General Directorate for Social Advancement, Ministry of Social Affairs, Tunisia) agreed with the importance of unifying terminology across ministries. In her work, she depended both on national statistics and administration data. In each province, there was a government committee represented by the various ministries to issue disability cards and provide the various services to which persons with disabilities were entitled. Aside from the disability card registry, there were other sources of information such as the Ministries of Health and Education, but due to varying definitions there were discrepancies in the data. For example, the Ministry of Education considered persons with learning difficulties to have a disability, whereas the Ministry of Social Affairs did not. The Ministry of Labour had a registry of job seekers which could be accessed if requested. The Ministry of Social Affairs had carried out field studies to help improve services and was now embarking on a mapping project to enable them to know the actual number of persons with disabilities in comparison to the official statistics. The actual difference in numbers was not very significant.

15. Mr. Hamoud bin Mardad bin Hamoud al-Shabibi (Assistant General Manager, General Directorate for Persons with Disabilities, Ministry of Social Development, Oman) stated that national statistics were not helpful in developing policies in the field of disability. They were not inclusive, not updated and not accurate and were used more as an indicator. For accurate data on employment status, education level, type and degree of disability, they depended more on the disability card registry. Oman would soon have a unified registry for all individuals in the country based on their unique identification number, which would be used by all ministries. The registration mechanism was being modified to be in line with the Washington Group questions. The Ministry of Health did not determine if a person had a disability, but only gave their medical status. The standardized evaluation was completed by the Ministry of Social Development based on functional capacity

in relation to the environment (e.g. rural vs urban) and personal factors (e.g. family situation). This evaluation determined their level of disability and the kind of interventions and support they needed.

16. He further noted that statisticians often did not know how to think outside of the box. They were rigid in their data collection methods and often did not understand the cultural dimensions or they lacked awareness about disability. The Ministry offered to provide statisticians from the NSO with training about disability, but there was no interest. They needed to sit down together and discuss who would benefit from the survey and how to take the needs of the Ministry into account.

17. Mr. Sameh Said Abdel Aziz Shady (Researcher and Manager, General Directorate for Population and Social Research and Studies, General Authority for Urban Planning, Ministry of Housing, Egypt) commented that the identification of persons with disabilities should be done in line with international standards. It was important to identify what type of information was needed and who was the target group when gathering data. There was a study conducted in Egypt which found that the number of individuals with polio was very high in two villages because of traditions against vaccinations in addition to a lack of awareness about their importance in relation to health. It was important to provide training and awareness to reduce stigma but also to educate citizens about issues related to consanguineous marriage. CAPMAS was the main source of information, but this data was different from the data in line ministries. The General Authority for Urban Planning was very important because they planned all new cities and updates to cities, so they had to base their work on sound data. With input from seven line ministries, the Authority made a pioneering effort to create a guide for planning standards in Egypt to identify the services needed by persons with disabilities regardless of how they are classified. These guidelines were adopted and were used by the Ministry of Housing.

18. Dr. Azza Mohamed Badr (Technical Officer, Information, Evidence and Research Department, Eastern Mediterranean Regional Office, World Health Organization, Cairo) said that her work involved strengthening civil information and data registration. If registries did not remove people who died, then they would not be accurate. The WHO recommended assigning a national number to each individual for their lifespan, and this registry could provide sound and correct statistics. If all ministries used the same registry this would help identify duplications. Disabilities could be registered at birth, or when children enrolled in school with their identification number. The WHO Disability Assessment Schedule (WHODAS) offered 12 questions that could be asked when issuing identification numbers. Disability was a continuum, not a yes or no answer. Population registries could be a solution to the lack of data.

19. Mr. Alistair De Gaetano (Coordinator, Office for Disability Issues, Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing, Malta) commented that people who were working in statistics needed to know what a disability was. The definition used in the CRPD was not meant for classification but for anti-discrimination purposes. When it comes to gathering data, and providing services suited to a person's needs, it is important to look at functioning rather than just refer to a set list of disabilities. Autism was not an illness and using the term "disorder" medicalized it and caused fear. Now the term Autism Spectrum Condition (ASC) was being used and resulted in a different medical trajectory. When he was diagnosed with autism and told he had a disorder, it took him a long time to understand what was wrong with him. A person with autism needed support and accommodation and should be classified by level of functioning rather than just having a disability.

20. Mr. Alioune Haidara Mohamed Lehib (Director, Directorate of Persons with Disabilities, Ministry of Social Affairs, Childhood and Family, Mauritania) said that Mauritania had only recently begun collecting statistics on persons with disabilities. There were multiple sources of data, but the NSO was the primary and official source. The 2013 census had gaps and produced an extremely low and inaccurate prevalence rate of 0.96 per cent. Persons responsible for conducting the census were not well trained and the NSO itself confessed that the results were deficient. As a result, one of the priorities for the national plan 2010-2016 included holding a specific survey on persons with disabilities to have real statistics. They also started issuing a disability card to establish a registry linked to the national ID number, which could be used to identify services. So far, they had covered the capital and were now working on expanding to the provinces. The five-year plan was led by the

Multisectoral Council for the Promotion of Persons with Disabilities, but they were working with all concerned ministries. They also used data collected by service-oriented organizations that assisted persons with disabilities and were working with them to support more persons with disabilities to obtain a disability card.

21. Mr. Peter Fremlin (Consultant, International Labour Organization (Geneva)) commented that in forming disability policy, qualitative data collected from field studies and sample surveys about the lives, experiences and barriers that persons with disabilities faced were often more useful than overall numbers. Often data was not used because it simply did not exist, but data was not required to have universal design. Administrative data could tell you what types of services were available, but it could not tell you how accessible the environment was to obtain these services.

22. Mr. Amro Abbas (Board Member, AOPD, Egypt) noted that very discrepant figures could lead to a decline in services like education and health. The data was also limited due to inconsistent classification of persons with disabilities.

23. Mr. Abu-Farrash commented that administrative records were a very important source of information in addition to data collected using the Washington Group questions. They provided information about individuals but not about the surrounding environment. Their comprehensiveness also depended on the type of classification system that a country had in place. If a person did not have a medical report, he/she might not be registered. This applied to all ministries, and if there was no clear diagnosis, then the person would not be provided with services. Persons with disabilities were not compelled to register if they did not need services, as the services were provided on demand. Registration data was important for allocating budget lines, which might not be possible using only population data from censuses.

24. Ms. Orsolya Bartha (Senior Advisor, International Disability Alliance, New York) stated that at the global level, comparable data on disability still did not exist. What had been made clear so far was that everyone had different sources of data which they used, but they did not have a real picture about the situation of persons with disabilities. This meant that government policies were not accurate because they were not based on statistical evidence and they were not reaching all persons with disabilities. Thus, countries were unable to monitor the progress achieved for persons with disabilities for their inclusion into society. This meeting marked a crossroad: policymakers were brought together with statisticians to solve this problem. One of the main challenges that kept repeating was the question of what was a disability, what was an impairment, what was functionality, and how could persons with disabilities be identified. Using the functional approach to identify disability and using the Washington Group Short Set of questions would provide evidence-based data that supported policymaking and which could be used to report to the global level to show whether countries were creating inclusive societies in line with the CRPD and SDGs. This meeting was an opportunity for partnership and dialogue.

25. While initiating the discussion on developing disability indicators, Ms. Nauk noted that one of the most important issues for facilitating inclusion of persons with disabilities was the accessibility of their environment. This type of information, requested under SDG 11, was not available in national statistics or registries, but it was also difficult to measure. She asked the participants to share their views on the factors which were most important to measure to make societies more inclusive.

26. Dr. Abdulaziz Farah (Strategic Planning Advisor, Qatar Social Work, Qatar) replied that transportation and movement from one place to another were important issues which needed to be measured. Mr. Abu-Farrash added that the accessibility of public buildings was also an important issue, because persons with disabilities would be able to reach a certain destination, but they could not get into the facility. Jordan had building and construction codes on accessibility, but buildings might not be applying those standards.

27. Ms. Soha Farouk (Associate Programme Officer, UN-Habitat Regional Office for Arab States (ROAS), Cairo) commented that UN-Habitat was concerned with human settlements and shelters and that it carried out its work based on the New Urban Agenda, which included issues of accessibility for all persons in society. The

indicator for transportation in SDG 11 measured how accessible public transportation was and how far persons with disabilities had to travel to get to it. Another indicator under SDG 11 measured the availability of public spaces for all people and the ratio to the number of buildings and constructed blocks in the area. Universal design was based on the principle that the environment should be equally accessible to all regardless of circumstances. Another indicator was how far civil society organizations were involved in urban planning – they should be involved and could help to hold policymakers accountable.

28. Ms. Alhusaini mentioned four basic areas of priority related to accessibility: infrastructure/buildings, transport, electronic accessibility, and products/services. The main objective behind accessibility was the integration of persons with disabilities, so it was important to measure the extent to which buildings and services were accessible. Dr. Eldeep added that in his opinion, infrastructure was most important, as the design of buildings should be accessible. Dr. Badr added that the percentage of public buildings that were disability friendly should be measured. The percentage of accessible public transport and hospitals, health centers, and schools should also be measured. Mr. De Gaetano clarified that universal design, in which accessibility was universal, was different from reasonable accommodation.

29. Mr. Abu-Farrash stated that statisticians collected information about the number of public buildings, but an indicator would need to be developed for measuring their accessibility, like a checklist that a person with an engineering background could use to assess and rate each building with a certain percentage of accessibility.

30. Ms. Bin Brahim commented that it was important first for persons with disabilities to have transport to access services. In addition, once they arrived they needed to be able to communicate with service providers. In Tunisia, there was a law mandating accessible facilities, but it had not necessarily been implemented and technical standards had not been applied. Mr. Inabi agreed that buildings should be accessible in their design, but so should communication and services. In Palestine they had met with bank owners to improve accessibility standards in banks.

31. Mr. Mohammed Baghdadi (Head of Guidance and Support, Division of Prevention, Accessibilities and Assistance, Directorate for the Promotion of the Rights of Persons with Disabilities, Ministry of Family, Solidarity, Equality, and Social Development) emphasized the problem of implementation and the necessity to show commitment to make buildings and services accessible in cooperation with other ministries. After a dialogue was held with all agencies and civil society, Morocco established indicators on accessibility of public transport, technology and communication.

32. Dr. Al-Samman noted the importance of having accessible tourist sites. In Aswan governorate they had worked on quantifying the temples and setting standards for ramps and materials to facilitate tourism for persons with disabilities. It would also be useful to have an indicator for how many persons with disabilities were located near public parks and whether they could move within them easily, and whether the washrooms were accessible. The Egyptian Ministries of Justice and Social Solidarity investigated the accessibility of judicial services and facilitated the construction of ramps, accessible washrooms and elevators. Ms. Noman added that it was important to have an integrated environment and take also into account persons with visual and hearing disabilities. Schools should have to provide the necessary aids for these students so that all children could get an education.

33. Mr. Fremlin said that accessibility meant something different to each person with a disability. Many buildings were said to be accessible but in fact they were not – an indicator should quantify the number of accessible buildings, but in conjunction with a standard or auditing process to ensure they were accessible. Special priority should be given to making new buildings and new public procurements accessible, keeping in mind the various needs.

34. Mr. al-Shabibi commented that there was a need to raise awareness among public planners in Oman. In 2013 he organized a workshop with Rehabilitation International on Article 9 of the CRPD. Engineers were invited but their mindset was focused on physical disabilities; other types of disabilities were not clear in the

minds of planners. Most websites and transport were accessible in Oman. One of the mobile phone companies provided a package for persons who were hard of hearing. Many buildings had accessible facilities with ramps, but there was no auditing process to ensure they complied with accessibility codes. Oman had started a project on implementation of the CRPD in collaboration with CSOs and the private sector, in which they had mapped what ministries and companies were responsible for. There would be key performance indicators and each government agency was responsible for reporting on the extent of their implementation. Upon receiving the final list of observations following the discussion of Oman's national report in the CRPD Committee in February 2018, the Country filed the list with the Cabinet with the recommendation that each observation be directed to the relevant agency responsible for implementation and periodic reporting. The Prime Minister would soon be issuing a decree to oversee the implementation of the list of observations. With respect to reporting on the SDGs, the Supreme Council for Planning was responsible for compiling the national report and the Ministry of Social Development was working on establishing indicators for implementation.

35. Ms. Nauk summarized that the main priority was to have indicators for measuring accessibility of (i) infrastructure and public buildings, (ii) transport, (iii) pavements, and (iv) participation in urban planning. Moving on to the next area for establishing indicators, she inquired about the importance of measuring violence and abuse against persons with disabilities, as well as health care coverage and out of pocket expenditures for health services. She asked whether it was more important to know about (i) the availability and accessibility of health services or (ii) whether these services were affordable, because in many countries, even with insurance, out-of-pocket expenditures could be very high, especially for people with disabilities. She further inquired how important these two indicators were for policymaking.

36. Mr. Mohamed stated that Sudan was prioritizing the issue of health and the Ministry of Health was working with the WHO. They had done a mapping of rehabilitation and health services in relation to their location, if they were public or private hospitals, types of services and treatments offered, and the cost. They had also distributed a form to persons with disabilities in the provinces to measure the type of services available and their cost. They were also considering measuring the number of individuals covered by the general health scheme under SDG 3.8.1 with a plan to provide universal coverage by 2020. They had achieved coverage of around 60 per cent, but had not been able to get good information about the number of persons with disabilities who were covered. The NSO did not use the Washington Group questions in the last census, but hopefully in the next round they would be able to identify more accurately the percentage of persons covered by health insurance disaggregated by type of disability.

37. Mr. Inabi stressed the importance of providing and regulating comprehensive universal health insurance for persons with disabilities. Some basic services and medications were not provided. The health insurance coverage should include all basic needs.

38. Mr. Baghdadi commented that when Morocco developed its national plan for persons with disabilities, an indicator was included to quantify the preventive health measures taken to prevent disabilities. Morocco also had a programme targeting vulnerable groups with low income to obtain health services for free.

39. Ms. Abou Khalil remarked that both health indicators would be important. Persons with disabilities had difficulty in obtaining health services but also in paying for these services. Certain types of disabilities required taking certain measures to prevent deterioration, which could be very costly. The State should provide health services to persons with disabilities, but the quality of these services was also important. Lebanese law stipulated that each person with a disability was entitled to the disability card, which ensured the State would cover their health services. However, persons with disabilities in Lebanon and across the Arab region instead often contacted DPOs in search of services.

40. Ms. Nauk added that the question was to know whether people could really access health services, and how it could be measured. Some people might have health cards provided by the State, but they did not bother renewing them because they were not happy with the quality of services. If there were statistics which showed

out-of-pocket expenditures were higher for persons with disabilities, this might give an indication about the accessibility of services.

41. Ms. Al-Samman noted that Egypt had taken steps through legislation to expand health insurance coverage, but free medical centers that provided different types of assistance to persons with disabilities might not necessarily be providing good quality services. Statistics did not provide information about the quality of service.

42. Mr. Abu-Farrash noted that a low level of out-of-pocket expenditures could indicate that health coverage was high, or that people were not seeking medical services. Ms. Bartha suggested having an indicator which measured the percentage of the population receiving medical services free of charge. Ms. Nauk pointed out the difference between who “should” receive free health care versus who received it. She suggested that an indicator which measured out-of-pocket expenditures for essential health care might be the best solution.

Annex*

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